

JOY M. VASS

WRITTEN STATEMENT

ON

MEDICAL DEVICES AND PATIENT/PROVIDER PERSPECTIVES

SUBCOMMITTEE ON HEALTH AND ENVIRONMENT

HOUSE COMMITTEE ON COMMERCE

APRIL 30, 1997

Hello, my name is Joy Maria Vass and I appreciate the opportunity to be with you, and to tell you my story. Approximately 12 years ago, I had my first heart attack while watching the evening news. At that time, the doctors discovered that I have Coronary Artery Disease-Hypolipothermia -- a dual congenital disease in which extremely high levels of cholesterol collects in the arteries causing blockage. As a result, the heart suffers from a lack of blood and oxygen, which leads to severe angina, heart attacks, or death.

At the time of my first attack I was 25 years of age, and working in a relatively stress-free job in Virginia Beach. When my parents rushed to my bedside, doctors informed them that my cholesterol level was nearly 800 -- it should have been less than 200. I was immediately placed on a low fat diet, which I have followed consistently since that time; and was prescribed cholesterol-reducing pills, powdered drinks, beta blockers, and diuretics. I was told that I would live a relatively “normal” life, and although I had three angioplasties from 1986 to 1991, life was as “normal” as it could be. However, in 1991, I began to show signs of the onset of angina and the possibility of a major or fatal heart attack. I was rushed to the hospital where doctors held a conference with my parents and myself. We were told that I needed immediate bypass surgery.

On March 3, 1991, I underwent a quadruple bypass procedure. I recovered in record time and proceeded with my life, which included securing a master’s degree from the University of Mississippi graduating in the top 10 percent of my class. Shortly thereafter, my health began to deteriorate and I soon found myself again watching the shadows of twirling red and blue lights from the back of an ambulance. Doctors were astounded to find that after a cardiac catheterization only eighteen months earlier, three of my bypassed graphs were again more than 90 percent blocked. I was once again scheduled for yet another bypass in March 1993.

One week before surgery, doctors called to request a meeting between my parents and whomever else we deemed necessary. As we sat around a beautiful mahogany table, the doctors began a “show and tell” using my x-rays. Very reluctantly, but very candidly, the chief cardiologist told us there had been a change in the program. My surgery was being canceled because they didn’t feel that additional surgery would benefit me to any great degree. The discussion ended like a Dear John letter... “forgive us, but there really isn’t anything else we can do for Joy.” After fifteen seconds of silence, tears barely touching my face as they fell, my father (a high school principal who is now deceased), cleared his throat and said: “How do you tell my 32-year- old daughter who has been on the honor roll since the fourth grade, who went to Mississippi where she knew no one and became the first black female dorm director, who graduated from Ole Miss in exactly ONE year with a dual major and with all As and one B, who can walk into a room and immediately illuminate it, that all of this no longer matters?” But the doctors would not change their minds.

Consequently, for two years, I was on IVs, and heavily medicated with various heart medications, nitro pills which I took like Tic-Tacs, nitro spray, nitro patches, and pain killers. In short, MY LIFE WAS HELL! The final blow came when my insurance carrier “dismissed me.” I was forced to become labeled as “totally disabled” and had to collect Medicaid and Public Assistance. I further had to allow myself to be degraded by individuals of these organizations who snarled at me as if to say “Heart disease, yeah right, only old folks have that. Who do you think you’re fooling?” Since I was now on Medicaid, my mother, who is a retired nurse on disability, did some research, and from an old acquaintance, found a hospital that had the guts to try to make her sick child well again.

Around this time, I became pregnant and engaged. Naturally, given my condition, my doctors immediately advised me to abort. I refused because I truly knew how precious the gift of life is. I was willing to forfeit my own life for that of my unborn child, and I even signed papers that stated “IN THE EVENT OF MY DEATH” with my mother as a witness. But now I was in constant pain and could no longer shower alone. I had little or no daily mobility, and eventually became wheelchair-bound. Mercifully, God had another plan and after eight months of pregnancy, I delivered my stillborn son Kyle.

By now, my health was critical. My mother -- bless her heart -- remained the greatest trooper of them all. She was forced to endure double duty as her husband lay dying on the third floor of the hospital while her daughter was dying on the fourth floor. I was hospitalized off and on for months, slowly slipping away. My cardiologist refused to let it be over, and decided that it was time to introduce me to doctors who were working on an experimental surgery called TMR or transmyocardial revascularization. If I was willing, they would test me to see if I was an eligible candidate for the procedure. In doing so, it ensured that I could become the first qualified candidate in the Washington Metropolitan Area to receive the new laser surgery.

In brief, the idea for the procedure stems from the alligator and the way its heart functions. Instead of the heart relying upon the arteries for passage of blood, a laser is used to create tiny holes in the heart, thereby resulting in the heart receiving its necessary blood and oxygen through the holes instead of through the conventional human method.

In later November 1995, I was told that I would be the first TMR recipient, but because the surgery was pending approval from the Food and Drug Administration, there were some insurance problems. At 6:00 a.m. December 13, 1995, the morning of my surgery, my loved ones and I braved

the frigid temperatures and lack of sleep. That morning we learned that the final word had come from my insurance company and they would not contribute any financial resources because of the surgery's experimental status.

Believe me, I get "Joy" when I think about the doctor and nurses standing at the door of the family waiting room, searching the faces of my family and friends and saying something to the nature of "this one is on the house." This is how I am able to speak to you today without becoming totally winded, and not from the whopie cushion of my wheelchair.

I am now a part-time supervisor at Sears Department Store and am engaged to a new and wonderful man who understands that there have been times, when in the words of Langston Hughes, that "Life for me ain't been no crystal stair." I'd promised my niece, who was malnourished and neglected, that if I survived the surgery and God granted the energy to just "Feel like Going on," that I would adopt her. She's been with me since Christmas of 1995 and is here today with the real soldier - my Mom -- and a few other of my nearest and dearest.

Thank you for allowing me to share my story with you. I seek no personal gratification or sympathy, and, although another TMR is inevitable, my only purpose here today is to help extend to others who are suffering the words of the Reverend Jesse Jackson, "Keep Hope Alive." Again, don't cry for me, but shed tears for those who are not as fortunate as I to have family and a medical team that will go to the extremes of unconditional love and caring.

Finally, I hope that I will leave you today pondering about those individuals' whose lives are dangling somewhere between the stages of experimentation, red tape, FDA approval, insurance discrepancies, paper shuffling and death. Again, thank you for this opportunity, and always remember, when in doubt listen to your heart; for it beats the truth.

